Face to Face

Implications for policy and practice

- Bodily care of people with advanced dementia in care homes is time-consuming and laden with tensions but provides important opportunities to support personhood and challenge social exclusion.
- Consideration needs to be given to the skills and staffing levels required to care humanely for people with advanced dementia facing the end of their life in care homes.
- All health and social care staff, and families, require more education about non-verbal communication and embodied aspects of personhood to facilitate the inclusion of people with advanced dementia in relationships until the end of life and challenge social death.
- When decisions are being made about the care of people with advanced dementia, and when assessing their response to the care they receive, more attention needs to be paid to what they communicate in bodily ways. These non-verbal ways of communicating need to be taken seriously as intentional and informative alongside the views of family and health and social care professionals.
- Care providers need to take responsibility for the emotional care of their staff so that they can continue to care with compassion over a prolonged period of time. This may help alleviate the problem of high rates of staff turnover in care homes which undermines good relationships.

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Face to Face:

Relating to people with dementia until the end of life in care homes

As Scotland prepares its third National Dementia Strategy, this research highlights the importance of supporting people with advanced dementia to remain actively involved in their relationships. Paying more attention to the body can increase the scope and opportunity for relationships, and improve the quality of care.

Key points

- Examining interactions between care staff and people with advanced dementia challenges dominant societal views that advanced dementia 'takes away the person' and shows that they remain actively engaged within their relationships until the end of life.
- The social exclusion of people with advanced dementia within their relationships and within decisions about their care can be alleviated by paying more attention to embodied aspects of personhood and non-verbal communication and interaction.
- Hands-on bodily care of people with advanced dementia is not an unskilled task but complex and key to maintaining relationships with people with advanced dementia until the end of life.
- The feelings of residents in care homes are interconnected with the feelings of care staff. Failure to support care staff is counterproductive and undermines inclusive caring relationships.

Background

People with advanced dementia can struggle to maintain relationships and connections. As a result they can become isolated or socially excluded, whether they live in their own home or in a care home. They can also struggle to make their views heard in care situations, or when decisions about their care are being made. This situation is called social death, because the person with dementia is no longer seen as being active in their relationships (Glaser and Strauss, 1965).

Assumptions about the effect of advanced dementia on a person may influence whether they experience social death or not. A common assumption is that advanced dementia takes away the person. This assumption is based on the view that what makes us a person is our cognitive ability, and if this is severely damaged by dementia, then personhood is lost. However, there are other ways to understand personhood.

One such way is to recognise the embodied nature of human beings and that we are in the world through the vehicle of our body (Merleau-Ponty 1968). This means aspects of personhood are incorporated into the body. Research with people with advanced dementia has shown that habits of a lifetime can become embedded as memories in the body, even when a person is very forgetful. Kontos (2004) found that '...Gestures, movements of the body, limbs, hands, head, feet and legs, facial expressions, eye behaviour and posture carried implication and meaning. ...they played a large role in inter-personal communication, and often conveyed praise, blame, thanks, support, affection, gratitude, disapproval, dislike, sympathy, greeting or farewell and... were intentional, informative, communicative and interactive' (Kontos, 2004, p.835).

Also, in face to face interactions, such as moving together to music, a connection can be made and, as with all of us, subtle aspects of the person which could easily be overlooked emerge in the interaction between people (Zeiler 2013).

The study

The aim of this ethnographic study was to understand how care staff and residents in a care home relate to each other and what role the visible body can play in challenging social exclusion. The study took place in a medium sized care home in Scotland where all residents had a diagnosis of dementia. The researcher, also a registered nurse, spent 10 months (207 hours) in the care home working alongside care staff and residents helping to wash and dress people, assisting at mealtimes, keeping people company and taking part in the life of the care home. There were 24 interviews and three group discussions with staff, and residents' case notes were examined*.

Findings

Three main themes were important in understanding how care staff and residents related to each other:

- Bodily care
- Learning about and supporting embodied aspects of personhood
- Interconnections between the feelings of residents and care staff

Bodily care

The average age of residents was 90 years old. Most residents were frail and, as well as having dementia, had various medical conditions. Fifteen residents died during the study. Most residents needed help to wash and dress, to go to the toilet, to move around the building and at mealtimes. As a result, most of the staff's time was taken up with bodily care and this was a key part of the way staff and residents related to each other.

Many care staff experienced giving bodily care as an opportunity to spend time with residents and connect in a significant way, which they found rewarding, rather than a task to be completed so the care home could run smoothly:

> "I think it's really hard, I mean Penny, that's heart breaking isn't it because I'd love for her to be able to talk to me and tell me all the cool stuff that she used to do, it's hard. But it's really rewarding, like the other night I put her to bed and said 'goodnight Penny, God Bless' and she said 'good night' back and I was like 'oh we've just had a conversation' and that was really really cool….that made me smile lots…"
>
> (Debra, staff member)

These connections continued, even when someone was imminently dying:

> "You almost feel it …you maybe sense a change in the person's breathing, they come more relaxed or calm or the eyes open, they look directly at you, close again, just wee things."
>
> (Hilary, staff member)

*pseudonyms are used throughout

Interactions with residents during bodily care and paying attention to what they were visibly communicating was a way of understanding what they were experiencing:

> "...it is hard to explain how you can read that there is pain in (Penny's) face, you know, but the fact that she was rubbing and she didn't look as happy as usual, then she's not…we…we got the doctor to see her and she actually has quite, you know, bad knees and I try to say, they will, you know, be swollen and things, so she's on like regular painkillers now."
>
> (Zoe, staff member)

It was clear that people with advanced dementia can be very active when they are interacting during bodily care, which could raise tensions for staff, for example at mealtimes:

> "...you don't force somebody if they don't want to eat and they are making that clear to you whether it's pushing your hands away or spitting food out you've got to respect that, so that's tough from our point of view because you want them to get their nutrition, you want them to have fluids but at the same time you have to respect their wishes..."
>
> (Hilary, staff member)

Seemingly simple things like having breakfast or having a wash become much more complex and time consuming when someone has dementia and may resist the help offered.

Dilemmas around food and drink were intensified when a resident was recognised as becoming less well but there remained some uncertainty around whether they were dying, or might get better. Weight loss and reduced oral intake in someone who has advanced disease and is frail are a natural part of the dying process (Gold Standards Framework, 2016). The researcher observation below shows staff struggling to encourage Annie, a 97 year old who died less than three weeks later, to drink and take her medication, despite the non-verbal ways she was communicating that she did not want to:

> Three people described as 'failing' at handover – one of them was Annie. She was in the dining room for over two hours (this morning at breakfast). Throughout this time Edith (Staff Member), spent a lot of time with her trying to encourage her to open her mouth and swallow a high-calorie drink and her medication. Annie seemed very reluctant to take any fluids into her mouth or swallow. Annie barely had her eyes open and looked worn out.
>
> (researcher observation)

Bodily care of people with advanced dementia is commonly considered to be unskilled work. As health and social care policy supports people with dementia to stay in their own homes for longer, the care home population is becoming increasingly frail and in need of a high level of bodily care. These findings indicate that this is not unskilled work but key to challenging the social death of people with dementia.

Supporting embodied aspects of personhood

Giving people with dementia verbal instructions is not always effective, but care staff learned how to help residents in different ways. For example, Hilda was a lady who could walk but would get stuck on one spot. Asking her to keep walking didn't work but one of the carers worked out that holding her as if doing a Scottish dance helped Hilda:

> Anne suggested I walk with my right arm holding Hilda's right arm like doing the Gay Gordon' as this seems to help her to keep going forwards and go in the right direction.
>
> (researcher observation)

The memory of Scottish dancing is embedded in Hilda's body and when tapped into can help her to keep walking. This is an example of where knowing a person's culture and habits of a lifetime can help maintain a sense of connection and help care situations run more smoothly.

How we choose to dress is part of what makes us feel ourselves. This was no less important for people with dementia:

> "...if Annie doesn't have her socks, like, if you take her stockings off and you've not got her (bed)socks ready to put on then she'll... kick off... those silly wee things should be in the care plan, like, I like to wear bed socks."
>
> (Kathy and Nita, staff members)

A person with dementia may not be able to tell care staff these kind of details, which are unique to each person. It is important that if families are aware of how significant they are, they are given opportunities to make care staff aware and ensure these embodied aspects of personhood are included in care plans.

Interconnections between the feelings of residents and care staff

Care staff recognised that residents could pick up on how they were feeling without them saying anything:

> "...and they feel as well, if you are nervous they know that…they are very perceptive and they feel your feelings, you know, again they are very experienced people..."
>
> (Brenda, staff member)

This interconnection between the feelings of staff and residents could be positive for both and being together was comforting, even without conversation:

> "(If) I'm feeling rubbish or whatever ...I like to go and sit beside Penny (resident) and ...you cuddle in or whatever. That gives something for each of you, she ...I think she likes it too because sometimes she puts her hand on yours or she'll play with your hair or ...and it's quite nice, I feel quite calm sitting beside her..."
>
> (Vera, staff member)

However, within the busyness of the care home and the fact that most of the staff time was taken up with hands-on bodily care with little time left for social interaction, residents who needed more company could become distressed. Their distress led to staff feeling distressed:

> "It feels quite horrible just to be telling people, sit down. But because you're taking someone to the toilet or you're taking someone to bed, you know... the horrible thing about this job is you can't sit all day with one resident."
>
> (John, staff member)

If a resident was dying and they were frightened and needed extra company, this too was draining on the care staff:

> "I felt at the end Joanna was actually... I think she knew she was dying and she was frightened... to be alone... and it was draining on the team, I'll not pretend it wasn't."
>
> (Muriel, staff member)

At times, it was difficult for the staff to know how to deal with the strong emotions they felt by caring for people with advanced dementia with phrases such as '(controlling my emotion) costs me sometimes a lot', and 'you might have nightmares' indicating the highly emotional nature of care home life. There were also signs of emotional detachment with comments such as 'I seem to be getting very detached to it', 'I'm just burned out with it'. People can live with advanced dementia in care homes over a prolonged period of months or years which means care staff are regularly exposed to loss, pain, anxiety and death.

(cont.)

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